When should my baby be tested?

Be sure your baby is tested before you leave the hospital. If this is before 24 hours of age, the American Academy of Pediatrics recommends a second test before your baby is two weeks of age.

What happens to my baby's blood specimen after testing?

Newborn screening specimens are kept by the department for 21.5 years and then destroyed. During this time, some specimens may be used for medical research. Before any medical research is conducted, all identifying information is removed from the blood specimen card to protect privacy. If you have any questions or concerns, please contact the Newborn Screening Program.

Can the blood be returned to me following the testing?

No. However, state law provides you with the option of asking that a second specimen be obtained at the same time as the newborn screening specimen. You can keep this specimen at home with your baby's records or in another safe place. This second specimen may be important to your family at a later date for identification purposes.

What is supplemental newborn screening?

Supplemental screening includes tests for additional conditions that are not currently included in the Michigan newborn screening panel. Various laboratories offer this testing for an additional fee. However, it must be noted that not all supplemental screening panels include the same disorders. Some may not include all of the disorders that are currently mandated and screened for in Michigan. Therefore, supplemental screening should never be used to replace the state mandated newborn screening panel. For additional information about supplemental newborn screening, talk to your health care provider or contact the Newborn Screening Program.

Is there anything I need to do?

- Make sure your baby is tested. Ask you doctor or hospital staff if a specimen was obtained for newborn screening and sent to the Michigan Department of Community Health Laboratory for testing.
- If your baby is discharged from the hospital before 24 hours of age, take him/her to your health care provider for a retest before your baby is two weeks old.

- Check with your pediatric health care provider about your baby's newborn screening results.
- Follow your doctor's recommendations for any additional tests or medical appointments.

Any other questions?

Please talk to your health care provider or contact us at:

Michigan Department of Community Health Newborn Screening Program 3423 N. Martin Luther King Jr. Blvd. P.O. Box 30195 Lansing, MI 48909

Telephone: 517-335-9205 Toll-free: 866-852-1247 Fax: 517-335-9419

Website: www.michigan.gov/newbornscreening Email: mdch-newbornscreening@michigan.gov

MDCH is an equal opportunity employer, services and program provider. www.michigan.gov/mdch

Revised September 2004

100,000 copies printed at 6 cents each with a total cost of \$6,161.54

Michigan Newborn Screening Program

Step













The Michigan Department of Community Health wants to help your baby get an early start on the road to good health. When your baby is only a few days old, important steps are taken to detect rare but serious disorders. Using just a few drops of your baby's blood, the Michigan **Newborn Screening Laboratory** performs screening tests to check your baby for these disorders. If not detected early, these conditions can cause mental retardation or serious health problems. That is why the Michigan Department of Community Health tests every baby born in Michigan.

My baby seems really healthy. Are these screening tests really necessary?

Absolutely. Experience has shown that newborn screening is the only reliable way to find babies with these disorders early enough to prevent mental retardation or early death. Since most babies with these disorders appear healthy at birth, the special screening test can identify these problems before a baby gets sick.



What are the Disorders?

Disorder Name	What is It?	What Happens Without Treatment?	Treatment
Phenylketonuria (PKU)	Baby is unable to use a certain part of protein found in food and milk	Mental retardation	Special diet and blood monitoring
Maple Syrup Urine Disease (MSUD)	Baby is unable to use a certain part of protein found in food and milk	Severe disability or death	Special diet with blood monitoring; a medical plan for times of illness
Galactosemia	Baby is unable to use a certain kind of sugar (galactose) found in breast milk and infant formulas	Death in the newborn period	Replace milk products in the diet with a milk substitute
Biotinidase Deficiency	Baby is unable to use a necessary vitamin called biotin	Convulsions, hearing loss and mental retardation	Biotin supplement
Sickle Cell Anemia	Baby has sickle shaped red blood cells	Possible sudden death from infection	Daily penicillin
Hypothyroidism	Baby has a low level of thyroid hormones	Mental retardation and poor growth	Thyroid hormone replacement
Congenital Adrenal Hyperplasia	Baby has adrenal gland hormone abnormalities	Death in the newborn period	Adrenal hormone replacement
Medium-Chain Acyl- Coenzyme A Dehydrogenase (MCAD) Deficiency	Baby is unable to use fat as an energy source when sugars are unavailable	Seizures, coma or sudden unexplained death	Special diet and a medical plan for times of illness
Homocystinuria	Baby is unable to use a part of a protein found in food and milk	Developmental disabilities, poor bone development and blood clotting	Special diet and vitamins (vitamin B6)
Citrullinemia Argininosuccinic Aciduria (ASA)	Baby cannot remove certain waste products from the blood	Severe disability or death	Special diet and medicines that remove waste products from the blood

What happens if one of the tests is positive (abnormal)?

A positive screening test does not necessarily mean that your baby has one of the disorders. In fact, many babies have a slightly positive first screen for a variety of reasons. If so, a second test is required. Any baby whose screening test suggests a high chance of having one of the disorders will be referred to a medical specialist for confirmation of the diagnosis and treatment. The Michigan Department of Community Health will notify your baby's health care provider who will contact you with instructions for follow—up.

If my baby has one of these disorders, is there a cure?

Babies with these disorders cannot be cured, just as eye color or blood type cannot be permanently changed. However, the serious effects of these disorders can be greatly reduced or completely prevented if a special diet or other medical treatments are started early. Most children grow and develop normally when early diagnosis is followed by appropriate medical care.

